



Welfare of the Child Review

Report of a public consultative meeting held at the Royal Society of Medicine, London, 8 March 2005

1. Aim of the consultative meetings

In June 2004, the HFEA launched a review of its guidance on welfare of the child assessments in licensed fertility clinics. In order to gather the views of clinic staff, patients and other stakeholders, a public consultation was held between January and April 2005. This consultation consisted of a written consultation document, *Tomorrow's Children*, and a series of public consultative meetings held in Westminster, Glasgow, London and Manchester during February and March 2005.

The main purpose of the consultative meetings was to offer clinic staff, patients and other stakeholders an alternative method of feeding their experience and view into the review. The meeting also helped to:

- to promote discussion and debate on this key policy issue, thereby understanding differences in perspective and opinion;
- to involve practitioners, patients and other interested parties in the policy making process; and
- to encourage practitioners, patients and other interested parties to respond to the written consultation document.

2. Programme

The meeting in London started at 1pm with a lunch, during which HFEA staff and delegates were able to meet and discuss the issue on an informal basis.

HFEA Chair, Suzi Leather opened the meeting with a 10-minute introduction (see Appendix A for a transcript), explaining the reasons for conducting a review of welfare of the child assessments in licensed centres. She also outlined both the current guidance and the options in the consultation document for revising that guidance. The delegates were then split into three discussion groups, each containing an even spread of interests (doctors, patients, counsellors, nurses etc.). The groups took 30 minutes to discuss each of the three main areas of the welfare of the child guidance which are under review. Those areas are:

- What risk factors should be taken into account during a welfare of the child assessment?
- To whom should enquiries be made in order to gather relevant information?
- Do patients undergoing donor conception treatment or unlicensed treatments need a different kind of assessment?

3. Audience

Because the review focused on the welfare of the child guidance in the *Code of Practice*, the majority of participants were professionals or people with a personal experience of welfare of the child assessments. However, a number

of other stakeholders attended the meeting and provided a useful perspective in the discussions.

A total of 82 people registered for the consultative meeting, with 63 attending on the day (a drop-out rate of 23%). The breakdown, according to interest, of the 63 who attended was as follows:

Interest category	No.	%
Counsellor	15	24%
Clinician	5	8%
GP	1	2%
Embryologist	3	9%
Nurse	16	48%
Patient	4	12%
Social worker	2	3%
Other		%

4. Audience feedback

Of the 63 delegates at the meeting, 12 (19%) completed a feedback form. Of those who responded, 50% had heard about the meeting either from an HFEA mailing or from the HFEA website, 33% had heard from PROGAR, SEPAN or BAAF and 8% had heard from their workplace (the other 9% did not indicate). When asked an open question about why they were interested in attending, 75% stated professional interest, while 25% said it was to contribute to the consultation or to gain knowledge. Most respondents rated both the opening presentation and the meeting format as good. When asked how they prefer to respond to an HFEA consultation, 17% preferred to contribute through a workshop, 8% preferred to submit a written response and the remaining 67% liked to use both methods.

5. Summary of the discussions

Before delegates focused upon the policy options put forward in the consultation document, they were asked to discuss their views on the welfare of the child principle in the Act and how we should interpret it in the clinic.

A number of clinicians at the meeting questioned the appropriateness of the welfare of the child provision in the legislation. One delegate suggested that Parliament's intention was to isolate the few 'problem' patients, rather than to impose a routine assessment of all patients. A few argued for minimal assessment, unless there is a grave risk of significant harm. A professional would always have the right to refuse treatment if he or she felt uncomfortable about proceeding.

One clinical delegate wondered whether there needs to be a welfare of the child requirement in the legislation at all. His view was that welfare of the child

considerations are part of good practice in assisted conception and that clinics would continue to take such issues into account even if there were no legal obligation to do so. Another delegate reminded the meeting that people working in clinics regarded the welfare of children as an important principle long the 1990 Act came into force.

5.1 What risk factors should be taken into account during a welfare of the child assessment?

Current HFEA guidance expects clinics to take into account a wide range of medical, psychological and social factors which might impact upon the welfare of the child to be born. The consultation document presented the following options for amending the guidance:

- A only risk factors for medical harm should be taken into account
- B risk factors for medical, physical and psychological harm should be taken into account
- C risk factors for medical, physical and psychological harm and social circumstances should be taken into account

One delegate argued that the aim of welfare of the child assessments should not be to limit access to fertility treatments to 'super families', but instead to provide a mechanism by which clinicians could deal with the very exceptional cases where a high risk of harm to the potential child can be identified.

One patient suggested that IVF patients are probably less likely to pose a risk to their child than people who are able to conceive naturally. People who seek out fertility treatment have considered the issues carefully and are committed to being parents. Another patient said that she felt insulted by the welfare of the child assessment. In her view, doctors and patients should make a judgement about the suitability of the treatment between themselves.

A clinic staff member mentioned the case of a patient's partner being held on remand in prison, and another case where the patient's partner was affected by an inherited progressive disorder which would lead to deterioration of mental capacity and vision. In each case, the team felt it as problematic to proceed with treatment, although the clinic staff member wondered whether they weren't effectively 'playing God' by denying access to treatment.

Most delegates agreed that some social factors need to be taken into account during a welfare of the child assessment. But they were unable to agree about which social factors and how they should be considered. A support worker in surrogacy arrangements stressed that different cases might require different factors to be considered. Where a single woman seeks donor conception treatment, for example, clinics should take into account her social support networks. Another delegate pointed out that medical factors - disabilities or chronic conditions - are often less damaging to a child's welfare than psychological and social factors. Others made the point that whatever types of information is gathered, it should be factual rather than speculative.

One clinic staff member suggested that a wide range of issues – physical, psychological and social – should be taken into account. However, if problems of this kind emerge, the patients should not necessarily be refused treatment. She couldn't remember any cases in her clinic where patients were in the end turned down for treatment, although there were some cases where the patient themselves decided not to proceed.

Another clinic staff member said that if problems are identified regarding a patient, the information does not normally emerge through the formal assessment process, but through ongoing close contact that various professionals have with the patient. Often, the assessment required by the HFEA was considered a mere formality. It was even suggested that this formality sometimes gets in the way of a clinician trusting their intuition and following up concerns where they feel this is appropriate.

However, one patient representative insisted that having guidance is important in order to prevent arbitrary decisions being made by fertility specialists, who know little about the patients they treat. Overall, she felt that the guidance was important to clarify and regularise the welfare of the child assessment for patients.

The chair asked delegates to give a show of hands on the preferred option in the consultation document. None of the participants supported option A, but a majority supported option C.

5.2 To whom should enquiries be made to gather relevant information?

Current HFEA guidance expects clinics to write to the GP of each patient before treatment is offered to ask them for any information about factors which might adversely affect the welfare of any child to be born. If problems are raised, either by the GP or by the patient themselves, clinics are expected to contact other professionals or agencies for further information. The consultation document presented the following options for amending the guidance:

- A no welfare of the child enquiries should be made
- B information about risk factors should be provided by the patient themselves
- C information about risk factors should be provided by the patient and enquiries should be made to a third party if a problem is identified
- D information about risk factors should be provided by the patient and enquiries should be made to GPs routinely
- E information about risk factors should be provided by the patient and enquiries should be made to any third party routinely

The Chair asked how enquiries are carried out in clinics at present. Some clinics send out the relevant forms to the prospective patients before their first appointment, whilst others send the form to the GP after they have first seen the patient. Some delegates from clinics said that it is often difficult to get the forms completed by the GPs or that, because patients often change their GP, clinics can't be certain about the accuracy of the information gathered. If

patients are from overseas, clinics may not be able to contact their GP, making it impossible to carry out a full assessment.

Making enquiries to GPs

A number of delegates suggested that if GP enquiries are to continue, GPs should be asked very specific questions about information they might hold on the patient's file. It should be made clear that they are not invited to speculate about the quality of their patients as parents. Many GPs would be happier with their role in the assessment if this was made very clear to them.

One patient thought that contact with the GP should be an important element of the process, since it is normally the GP who knows the patient best. She also added that too often the assessment is done at the last minute, in a very rushed way, which is stressful for the patient, who might have to arrange an appointment with the GP at very short notice.

A GP pointed out that in adoption cases, where GPs are asked for statements, GPs are paid for this work. Also he stated that GPs don't receive welfare of the child forms very often and therefore may not be familiar with the information they are asked to provide. He thought it was unacceptable if GPs are asked (or had the impression that they are asked) to speculate about a patient's ability to be a parent. Some delegates asked why GPs couldn't be asked to fill in an assessment form at referral.

A representative from an adoption organisation pointed out that in adoption, most of the assessment is done by the prospective parents themselves (with support from professionals), and that the patients are asked to give their consent to further enquiries in case more information is needed. Self assessment shouldn't mean that patients are left to get on with it. Rather, they still need support and counselling in order to achieve a realistic assessment of their own situation.

One delegate suggested that in future patients should be given a standard list of questions to answer. The form could then be sent to the GP for verification. One patient thought that this might be a good way of giving patients a stake in the assessment process. A GP thought that the questions to be asked of GPs should be standardised, but that the decision about how to take information from GPs into account should be made by the fertility clinic.

Making enquiries to other agencies

One patient delegate argued that checking a patient's criminal record would be unnecessary and demeaning. However, another delegate supported routine police and social service checks to make sure that the parents were 'as good as possible'.

One clinic manager observed that involving social services, even for a few cases, is sometimes difficult. She recounted an instance of a hospital social worker who had refused to get involved in the assessment on the grounds that the children in question weren't yet born and that to exclude a couple from treatment was an infringement of the persons' human rights.

In a show of hands on the five different policy options presented in the consultation document, no-one supported options A or B. A majority of delegates supported option C, somewhat fewer delegates supported option D and a small but significant number of participants supported option E.

5.3 Do patients undergoing donor conception treatment need a different kind of assessment?

Current HFEA guidance lists additional factors that should be taken into account when assessing patients embarking upon treatment with donor eggs or sperm (gametes) or embryos. The consultation document presented the following options for amending the guidance:

- A donor conception patients should have the same assessment and information as patients using their own gametes or embryos
- B donor conception patients should have the same assessment as patients using their own gametes or embryos, but they should receive extra information and preparation
- C donor conception patients should have a more thorough assessment and extra information and preparation

Most delegates agreed that donor conception patients should not be assessed any differently from other patients. However, more information, particularly about being open with their child, was felt to be important for these patients. One delegate suggested that embryo donation should be treated differently and perhaps warranted a more thorough assessment of the patient(s).

Many delegates thought that encouraging patients to be open with their children about their donor origins is very important, but that agreeing to tell should not be a condition of being offered treatment. However, one participant suggested that if a patient is not ready to reveal the truth, they are not ready for treatment.

A counsellor pointed out that there are sometimes cultural issues surrounding donation. In addition, clinics see patients at such an early stage of their 'journey' that it was unrealistic to expect them to have plans about when and how to tell their child – a child which they may never conceive.

Counselling in donor conception

One clinician said that counselling should be mandatory in donor conception. However, delegates felt that it is important to be clear about the purpose of the counselling: is it to support patients or to assess them?

Another participant pointed out that the idea of counselling can be off-putting to some patients and that it was better to let patients benefit from meeting other patients and talking to people who had been open with their child about donation.

Appendix A: Introductory talk by Suzi Leather

Thank you to you all for coming along to today's consultative meeting about our public consultation on how to take into account the welfare of children born of assisted reproduction. My role is to set the scene for today's discussions: to explain why we are holding this public consultation; what questions we are asking and what we plan to do after the consultation.

But our primary goal today is not talk at you. We really want to hear about your experiences of using the guidance in your day-to-day practice and your views about how we might change the guidance in the future.

Why carry out a review now? Although it has been added to in the light of new developments, the guidance has not been thoroughly reviewed since the 1st Code of Practice in 1991. We know that clinics have some difficulties with aspects of the current guidance – we want the new guidance to address those concerns. But we also want to capture more than a decade of experience of carrying out welfare of the child assessments, experience that wasn't available when the first Code of Practice was drafted.

As you probably already know, the Department of Health will be carrying out a review of the legislation, the Human Fertilisation and Embryology Act 1990. However, we felt that we have to look at the guidance now because any changes in legislation probably won't happen until 2008.

What is welfare of the child? When Parliament passed legislation it decided that no group of people would be excluded from treatment. But instead clinics have to take into account the welfare of the child to be born of assisted conception. Parliament also decided that the HFEA as the regulator must produce guidance on what should be taken into account and how the assessment should be performed.

This puts a responsibility on clinics to take into account the welfare of the child for all treatments and also puts a responsibility on the HFEA to produce the guidance. In fact, welfare of the child is the one area of licensing that the Act obliges the HFEA to produce guidance on.

The welfare of the child principle is an important principle, but we know from talking to centre staff and patients that it is difficult to put into practice. Patients sometimes feel that they are being judged as parents and they can find the assessment difficult. After all, those conceiving naturally do not have any form of assessment.

What does our current welfare of the child guidance contain? In the current guidance, the treating clinician should discuss with their patients a range of issues. They're quite a jumble of different types of issues looking at medical, physical, psychological and social factors. They are the commitment to raise children; the ability to provide a stable, supportive environment; immediate and family medical histories; the age, health and ability to provide for the child; and the risk of harm to children including inherited disorders or transmissible

disease, multiple births, neglect or abuse and the effect of a new baby upon any existing child.

In the current guidance, who should be contacted to gather further information about the patient's medical and social history? At the moment, as most of you know, clinics are expected to contact the patient's GP, with the patient's consent, in order to gather relevant information and to ask the GP whether they know of any reason why the patient might not be suitable for treatment.

In our research leading up to the launch of the consultation, we identified a number of problems with this requirement:

- GPs often don't know their patient well enough to make an assessment
- Some GPs feel assessments are inappropriate or beyond their expertise
- Some patients don't have GPs
- Some clinics spent a lot of time and expense contacting and chasing GPs

During the course of the consultation – at today's meeting in particular – we want to discuss these issues in more detail.

Currently, clinics are expected to discuss a range of issues with patients undergoing donor conception treatment: a child's potential need to know about their origins and whether or not the prospective parents are prepared for the questions which may arise while the child is growing up; family attitudes towards a child; the implications if the donor is known within the family; and the possibility of disputed fatherhood.

But the guidance is a little unclear about whether these are issues which need to be discussed in order to prepare patients for donor conception parenthood, or whether these are issues which should be taken into account when deciding whether or not to offer treatment. As you'll see from our policy options, we want to clarify the situation for these patients.

In our consultation document, *Tomorrow's Children*, we consider three areas of the current guidance and lay out options for revising them. Under 'factors to be taken into account', the options are to focus upon:

- Risk factors for medical harm only (for instance, transmissible diseases)
- Risk factors for medical, physical and psychological harm (by physical or psychological harm, we mean neglect or abuse)
- Risk factors for medical, physical and psychological harm and social factors, which is the current practice (by social factors, we mean a stable relationship or the commitment to having children)

Under 'enquiries to be made', the options are:

- No social enquiries
- Medical and social enquiries made of the patient(s)
- Medical and social enquiries to be made of the patient(s), with enquiries to third party if a problem (such as a mental health problem) is identified

- Medical and social enquiries to be made of the patient(s), with enquiries to GP routinely (this is current practice)
- Medical and social enquiries to be made of the patient(s), with enquiries to the GP and other agencies (such as social services or Criminal Records Bureau) routinely.

In our consultation, we are also looking at whether we should make a distinction between patients having IVF and those using donor conception treatment. So, we are looking at whether those using donated sperm, egg or embryos should be given extra information such as discussing how they might tell their child that they are born from donated sperm, eggs and embryos.

We are also looking at patients who are having unlicensed treatment in licensed fertility clinics: treatments such as intra uterine insemination (IUI) or gamete intrafallopian transfer (GIFT). Currently, patients having these treatments must have a welfare of the child assessment - should this continue to be the case?

Your participation in today's meeting is very useful, but we would encourage you to respond in writing too: via our website, email or by post.

The public consultation ends on 7 April 2005 and new guidance will be published in the summer.

Appendix B: delegate list

Gordon Asher	University of Strathclyde
Mr Sam Abdalla	Lister Fertility Clinic
Dr Magdy Asaad	London Fertility Centre
Dr Sue Avery	Birmingham Women's Hospital
Alison Bagshawe	Guy's Hospital, London
Jeanette Bates	Brentwood Fertility Centre
Lotte Beasley	Epalan Ltd
Rosie Burbridge	Hammersmith Hospital IVF Unit
Dr John Clarke	Oxford University
Debbie Clarke	Hammersmith Hospital IVF Unit
Cathy Clarkson	Leicester Royal Infirmary
Jennifer Clifford	University College Hospital
Liz Corrigan	Centre for Reproductive Medicine, Bristol
Freda Cuffe	Brentwood Fertility Centre
Caroline D'Arcy	Guy's Hospital, London
Mrs Mary Elaine Dayeh	Winterbourne Hospital
Josephine Drag	Salisbury Fertility Centre
Sherry Ebanks	The Chaucer Hospital
Chriss Eftekhar	London Fertility Centre
Veronica English	British Medical Association
Mrs Mary Fagt	National Council of Women
Julia Feast	British Association for Adoption and Fostering
Suze Fisher	Woking Nuffield Hospital
Professor Jane Fortin	King's College London
Dr Paddy Glackin	City Road Medical Centre
Mollie Graneek	London Women's Clinic
Peter Greenwood	James Paget Subfertility Clinic
Prof Gedis Grudzinskas	The Bridge Centre
Ann Haigh	Barnardos
Emma Harmer	Leicester Royal Infirmary
Kim Hayes	Department of Health
Mrs Gosia Heeley	London Fertility Centre
Julie Hinks	Centre for Reproductive Medicine, Bristol
Pam Hodgkins	NORCAP
Khadija Ibrahim	Progress Educational Trust
Alison Inker	Centre for Reproductive Medicine, Bristol
Dr Caroline Jones	University of Southampton
Adriana Lambrianou	Tamba Infertility Support Group
Liz Latache	Bart's and the London Fertility Centre
Mrs Caroline Lewis	Woking Nuffield Hospital
Wendy Martin	Centre for Reproductive Medicine, Bristol
Mary McCann	The Chaucer Hospital
Samantha McLaughlin	
Jean Milsted	Buckinghamshire County Council
Olivia Montuschi	Donor Conception Network
Dr Kaori Muto	Shinsu University, Japan
Lynne Nice	Chiltern Hospital Fertility Services Unit
Karen Nobbs	Hammersmith Hospital IVF Unit

Caffy Nolan	Hammersmith Hospital IVF Unit
Sarah Norcross	The Daisy Network
Margaret Phelps	NCH South East
Grace Phiri	Brentwood Fertility Centre
Jill Richards	Salisbury Fertility Centre
Christine Rutter	Elizabeth Garrett Anderson & Obstetric Hospital
Mrs Rachel Smith	Centre for Reproductive Medicine, Bristol
Fiona Spearing	Shirley Oaks Hospital
Mrs Erika Spooner	Rosie Hospital
Alison Suggitt	University Hospital of Hartlepool
Sally Ann Swain	Bart's and the London Fertility Centre
Mr Boaz Tal	
Lesley Thompson	Bart's and the London Fertility Centre
Tricia Thompson-Newby	University Hospital of Hartlepool
Julie Tucker	Shirley Oaks Hospital
Dr Amanda J Turner	South East Fertility Group
Dr Geetha Venkat	London Fertility Centre
Mrs Kate Waldock	Rosie Hospital
Karen Woolfson	IVF World.com
Charlotte Augst	Human Fertilisation and Embryology Authority
Joyce Chia	Human Fertilisation and Embryology Authority
Suzi Leather	Human Fertilisation and Embryology Authority
Sarah Marsh	Human Fertilisation and Embryology Authority
Sara Nathan	Human Fertilisation and Embryology Authority
Vishnee Sauntoo	Human Fertilisation and Embryology Authority
Juliet Tizzard	Human Fertilisation and Embryology Authority